Anffas 60 anni di futuro
Le nuove frontiere delle disabilità intellettive e
disturbi del neurosviluppo

Nuova Fiera di Roma
28, 29 e 30 novembre 2018

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A Path to the Future: Promoting Self-Determination, Self-Advocacy, and Supported Decision Making for People with Intellectual and Neurodevelopmental Disabilities

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Supported Decision-Making

Receiving attention internationally as an alternative to substituted decision-making arrangements (e.g., legal guardianship or conservatorships)

Advocacy and legal communities raising concerns about the impact of substituted decision-making on the ability of people with disabilities to act as causal agents over their lives, exercising autonomy and self-determination
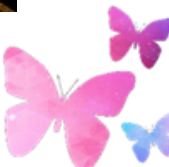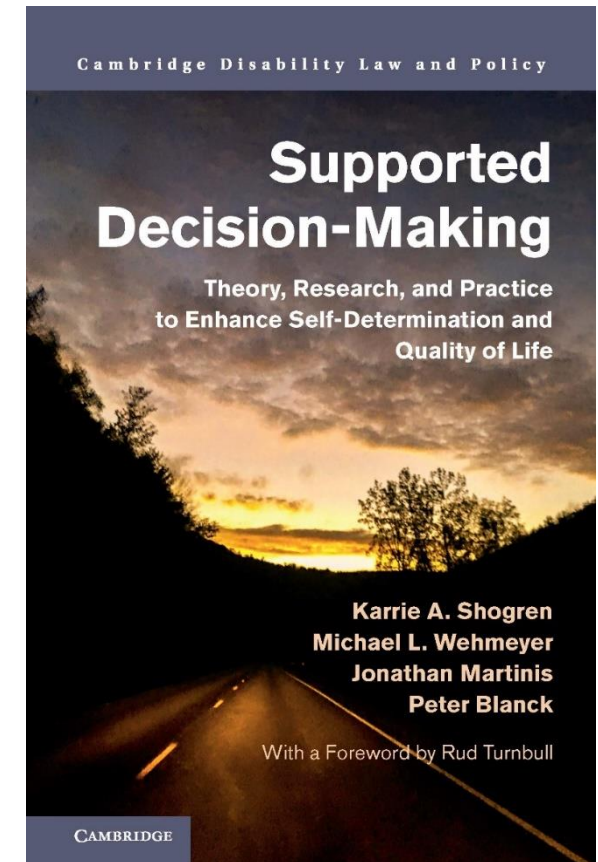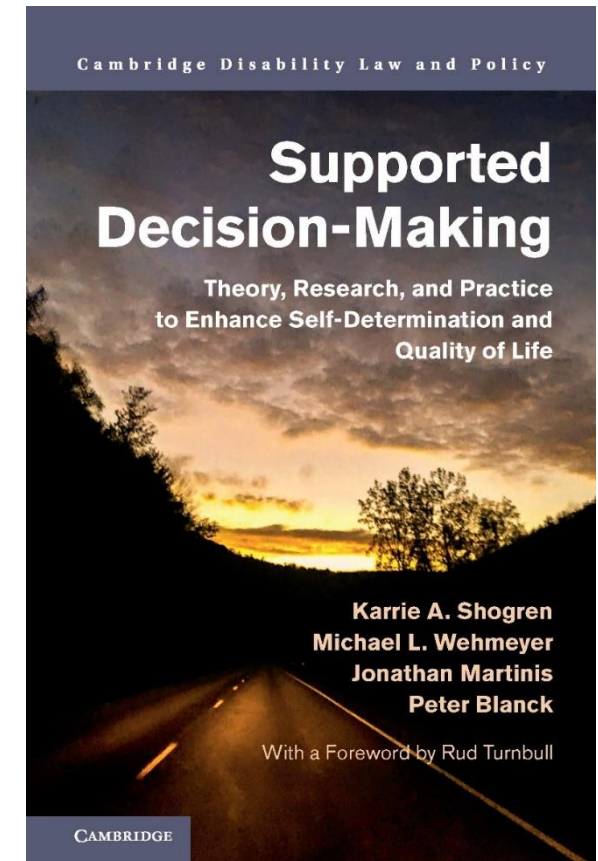
Supported Decision-Making and CRPD

United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that signatories need to

"take appropriate measures to provide access by persons with disabilities to the support they require in exercising their legal capacity"

SDM is named and described as a

"process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters"

Supported Decision-Making

Several countries and States in the U.S. have begun to conceptualize, and in some cases implement, SDM as a legal alternative to guardianship

Emphasize SDM as a legal option or framework for enabling people with disabilities to exercise their legal capacity

 Legal Standing

 Legal Agency

Supported Decision-Making

Need for frameworks that can be used, in practice, to promote the provision of supports for decision-making that enable people with disabilities to be maximally involved in decisions about their lives

Promotes self-determination and autonomy as well as, potentially, access to alternative legal arrangements

Supported Decision-Making Assessment

SDM Personal Factors Inventory
    Feelings
        I feel like I am free to decide for myself how to live my life.
        People in my life care about me.
    Experiences
        To what degree have you had opportunities to be involved in decisions?
        To what degree do you feel that you have been supported to successfully engage in the decision making process in the past?

SDM Environment Demands Inventory
    Environmental Domains
        Health   Relationships   Financial
        Legal   Community Living
    In **HEALTH** matters
        To what degree are opportunities available for you to make high risk decisions?
        To what degree are there supports available to enable you to make high risk decisions?
        To what degree is accessible information available to you to make high risk decisions?

Decision Making Support Inventory
    I know when a decision needs to be made.
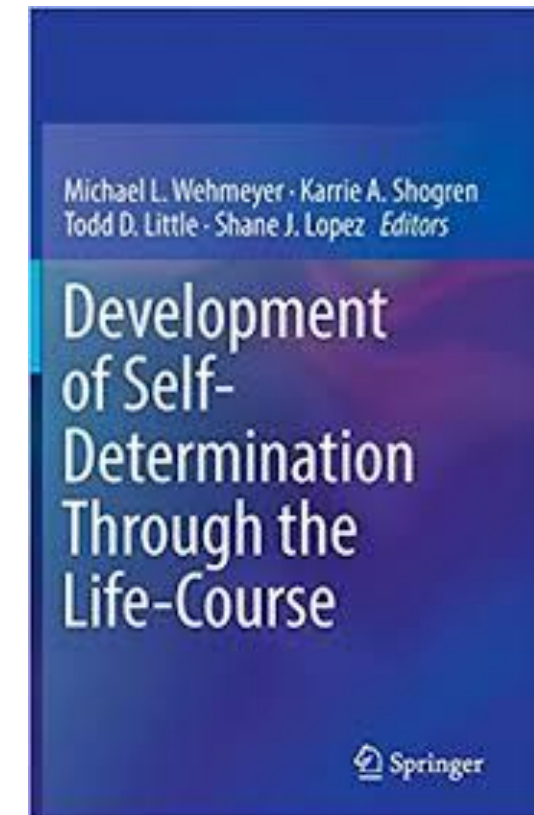   **Level of Support Needed (the support you need to do this)**
    I know that decisions lead to achieving a goal.
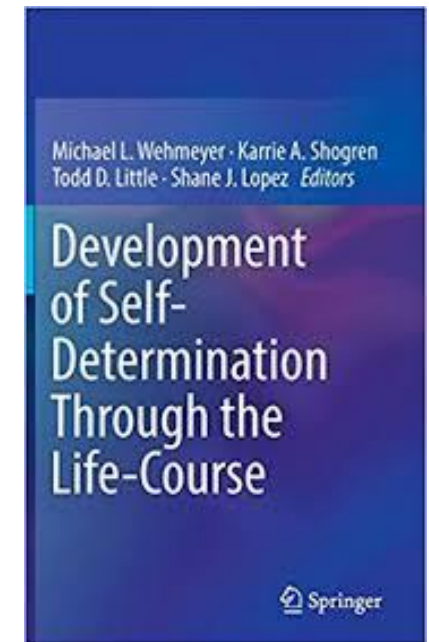   **Level of Support Needed (the support you need to do this)**

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Promoting Self-Determination Across the Life Course

Michael L. Wehmeyer · Karrie A. Shogren
Todd D. Little · Shane J. Lopez *Editors*

Development of Self-Determination Through the Life-Course

Springer

Causal Agency Theory

➢ Causal Agency Theory explains how people become self-determined.

➢ Self-determination is "a dispositional characteristic manifested as acting as the **causal agent** in one's life. Self-determined people (i.e., causal agents) act in service to freely chosen **goals**. Self-determined actions function to enable a person to be the causal agent is his or her life" (Shogren et al., 2015).

• One purpose of Causal Agency Theory was to align our work with research in motivation to construct a theory of the development of self-determination.

Elements of Causal Agency Theory

Essential Characteristics	Component Constructs	Component Elements
Volitional Action	Autonomy Self-Initiation	Causal Capabilities • Choice-making skills • Decision-making skills • Goal setting skills • Problem solving skills • Planning skills
Agentic Action	Self-Regulation Self-Direction Pathways Thinking	Agentic Capabilities • Self-management skills (self-monitoring, self-evaluation, etc.) • Goal attainment skills • Problem solving skills • Self-advocacy skills
Action-Control Beliefs	Psychological Empowerment Self-Realization Control expectancy Agency beliefs Causality beliefs	• Self-awareness • Self-knowledge

Intervention and Measurement

◦ The Self-Determined Learning Model of Instruction

  ◦ A teaching model design to support teachers to teach students to self-regulate goal setting and attainment...to enable them to engage in causal action.

  ◦ Students are supported to learn to self-regulate problem solving to set relevant goals, create an action plan to achieve the goal, track their progress toward their goal, and adjust their action plan or goal as necessary.

  ◦ Strong evidence base with students with disabilities.
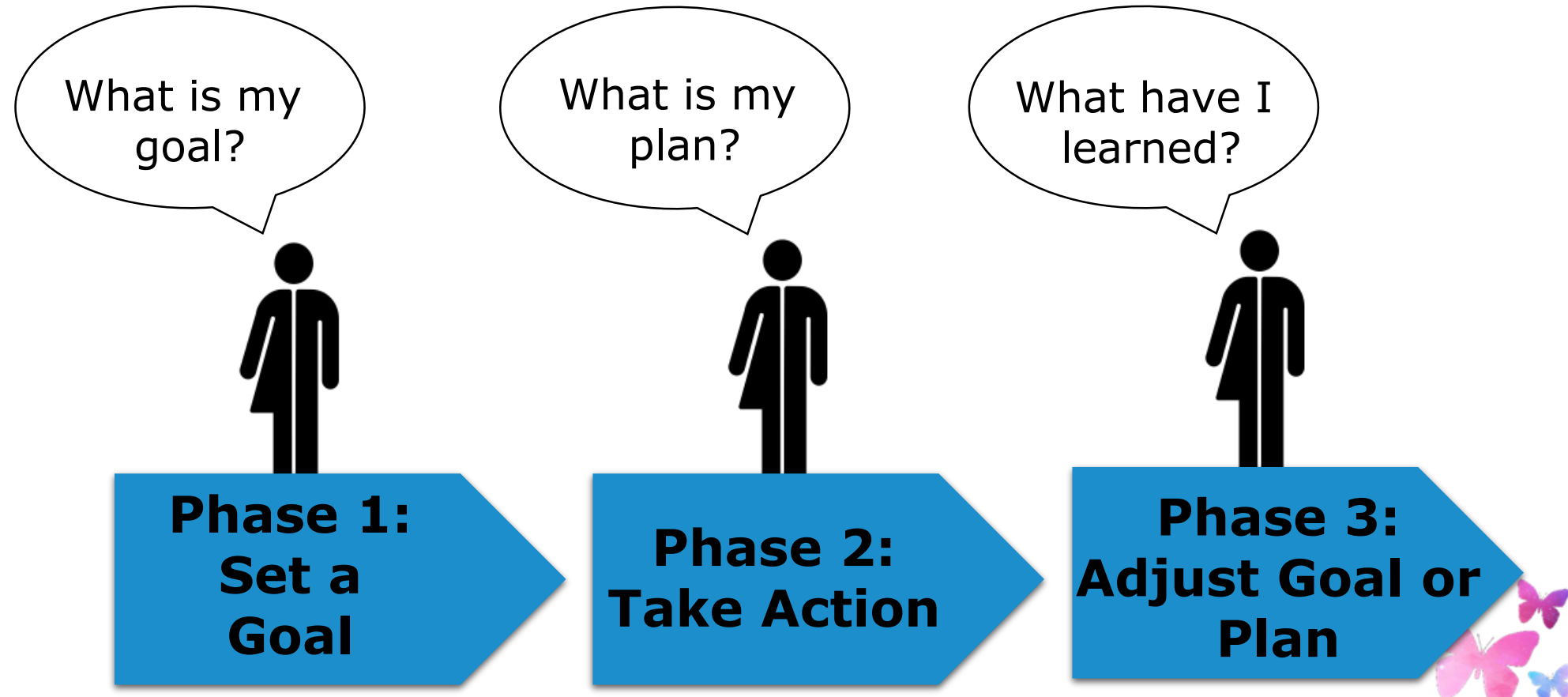
SELF-DETERMINATION.ORG

Teaching model that **enables students** to use a problem solving, goal-setting strategy to:

- Make **choices** and **decisions**
- Develop action **plans** for academic goals
- **Self-monitor** and **self-evaluate** progress toward academic goals

WHAT IS THE SDLMI?

What is my goal?

What is my plan?

What have I learned?

Phase 1: Set a Goal

Phase 2: Take Action

Phase 3: Adjust Goal or Plan

IMPLEMENTING THE SDLMI

- How much time does implementing the SDLMI take?
  - ✓ Individualized based on the strengths and support needs of the student

- What kinds of goals do students set?
  - ✓ Goals related to:
    - o Academics
    - o Vocational skills
    - o Transition
    - o Social Interaction

- How do teachers integrate the SDLMI with existing instruction?
  - ✓ Students often work toward goals throughout the day as opportunities arise
  - ✓ Teachers support students, but students self-direct the process.
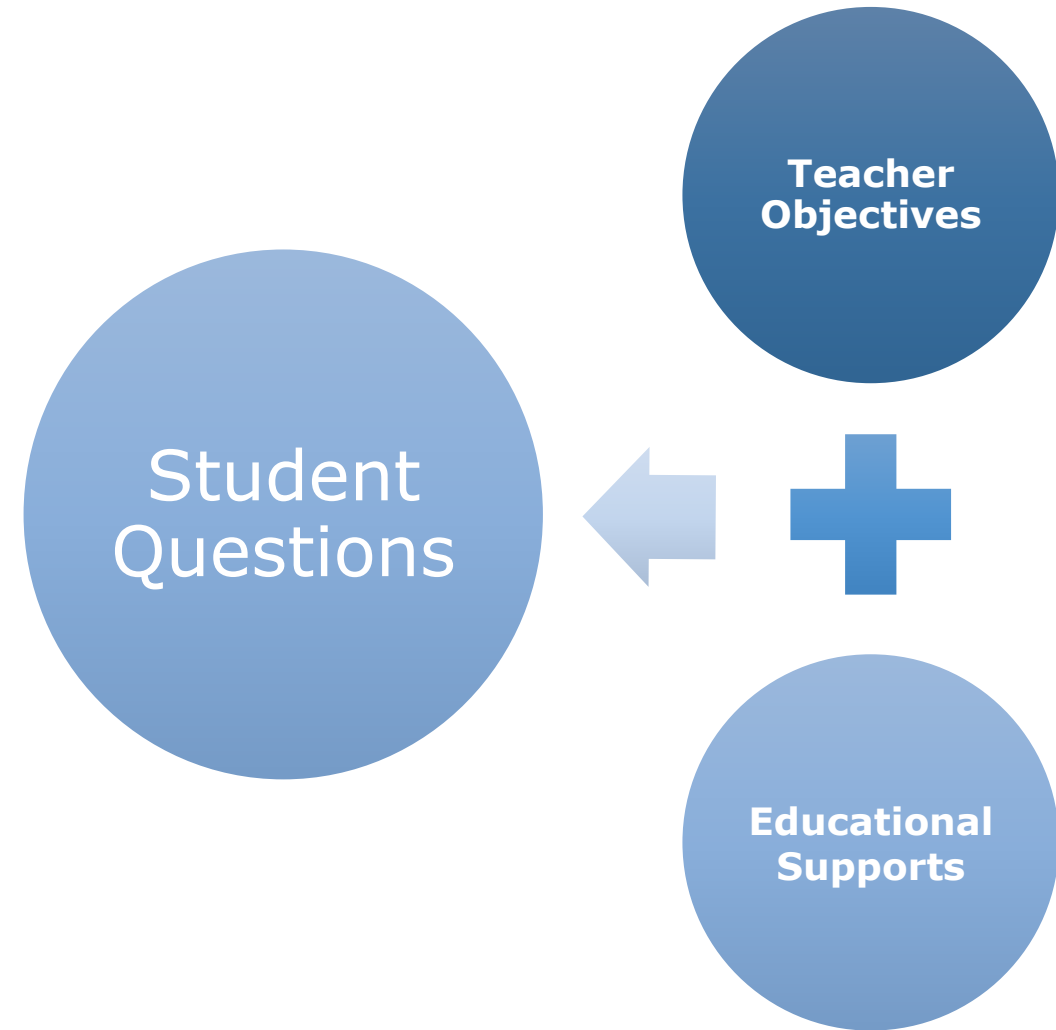
HOW TO USE THE SDLMI

Teachers can use the SDLMI in a variety of **settings** with a variety of **goals**:

- Academic goals linked to general education curricula
- Employment goals at job sites
- Independent living goals in the community

Guided by **Student Questions** as teachers meet **Teacher Objectives** and uses **Educational Supports**

The amount of time it takes **depends on the supports** each student needs
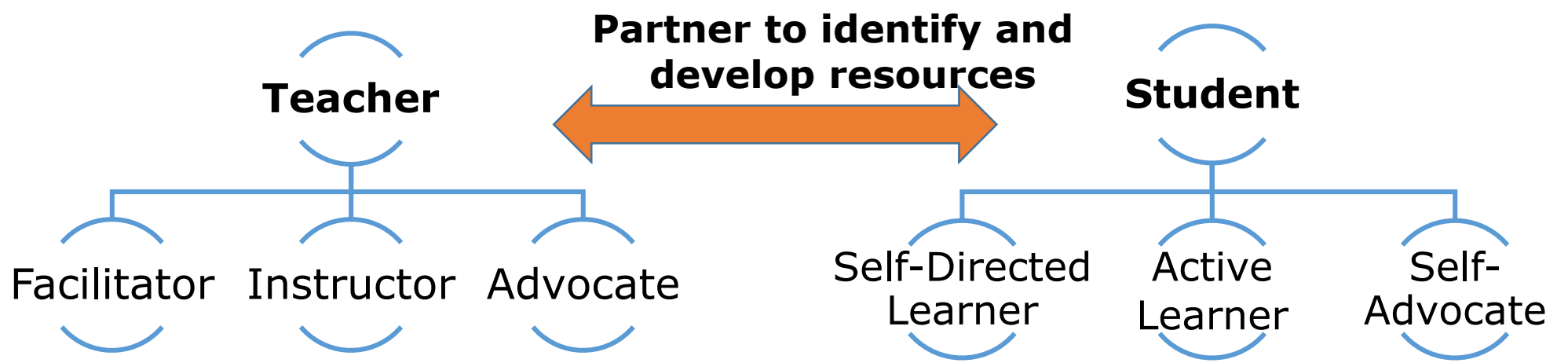
Teacher Objectives

Student Questions

Educational Supports

ROLES IN SDLMI

Teacher

Facilitator   Instructor   Advocate

Partner to identify and develop resources

Student

Self-Directed Learner   Active Learner   Self-Advocate
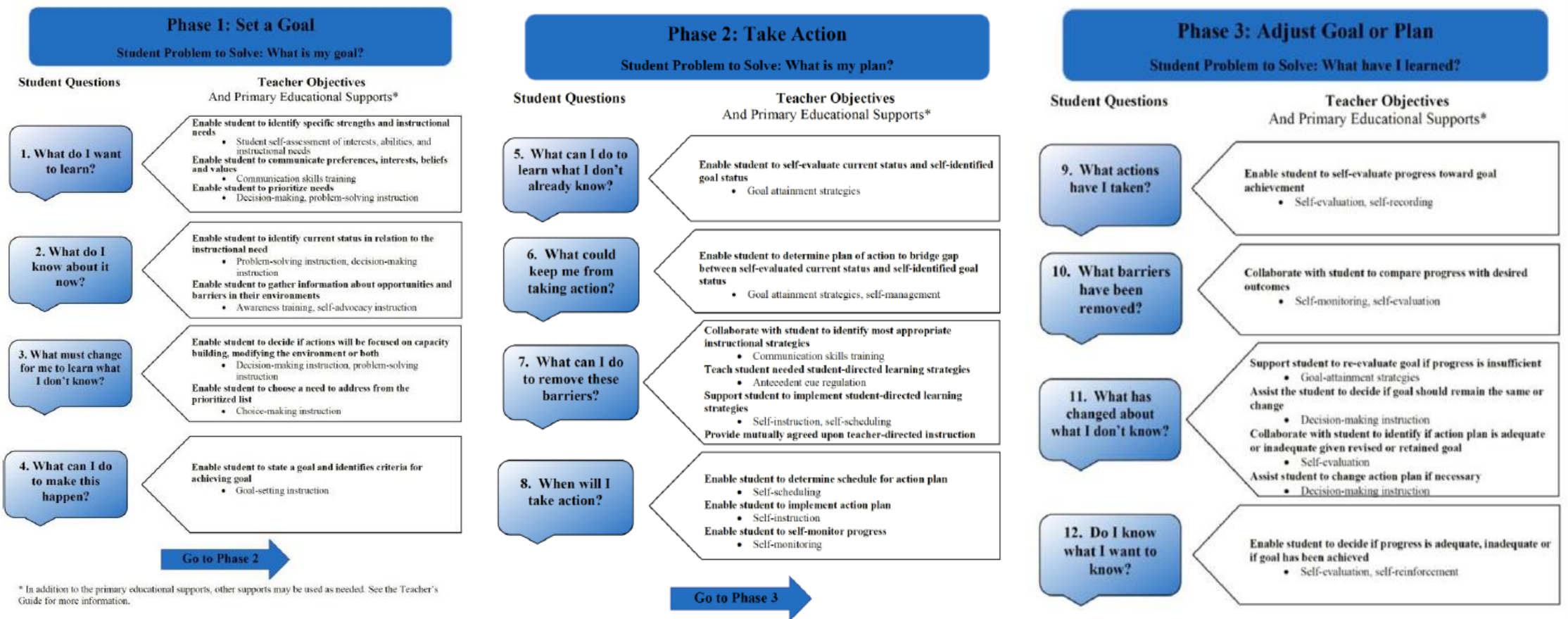
Self-Determined Learning Model of Instruction

Intervening to Promote Self-Determination
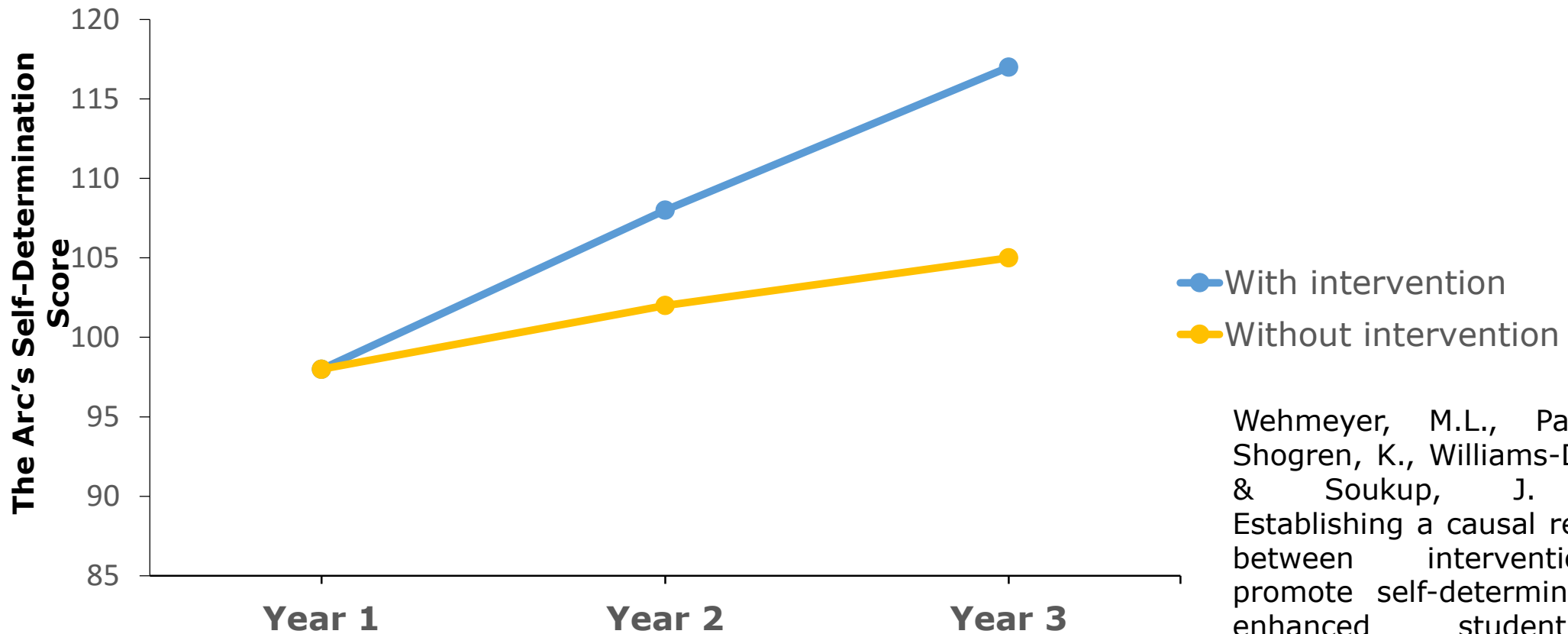
Wehmeyer, M.L., Palmer, S., Shogren, K., Williams-Diehm, K., & Soukup, J. (2012). Establishing a causal relationship between interventions to promote self-determination and enhanced student self-determination. *Journal of Special Education, 46*(4), 195 – 210.

SDLMI Impact Over Time

Intervention

3-year longitudinal study of self-determination intervention

High school campus

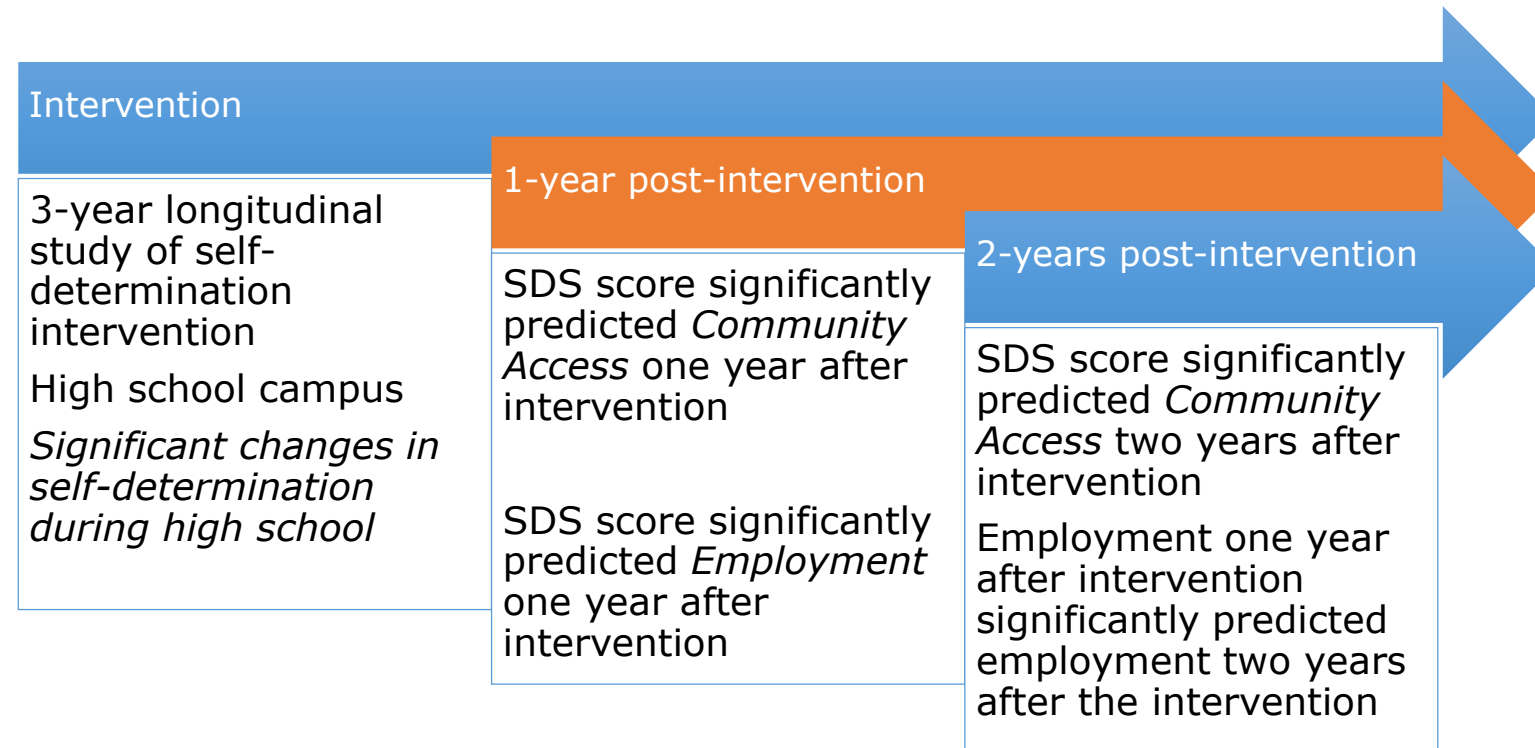*Significant changes in self-determination during high school*

1-year post-intervention

SDS score significantly predicted *Community Access* one year after intervention

SDS score significantly predicted *Employment* one year after intervention

2-years post-intervention

SDS score significantly predicted *Community Access* two years after intervention

Employment one year after intervention significantly predicted employment two years after the intervention

Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Rifenbark, G. & Little, T. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education, 48*(4), 256-267

Key Findings: Impact on Self-Determination

	Time 1	Time 2	Time 3	
	M (95% C.I.)	*M* (95% C.I.)	*M* (95% C.I.)	Latent *d*
AIR Self-Determination Scale				
Intervention Group	.00 (.00 – .00)	.07 (-.17 – .31)	.30 (.08 – .52)*	.31
Control Group	.16 (-.10 – .42)	.11 (-.15 – .37)	.17 (-.10 – .44)	.01
Latent *d*	-.20	-.05	.14	
The Arc's Self-Determination Scale				
Intervention Group	.00 (.00 – .00)	-.06 (-.21 – .10)	.24 (.06 – .42)*	.24
Control Group	-.01 (-.27 – .25)	-.06 (-.32 – .21)	.03 (-.26 – .33)	.05
Latent *d*	.01	.00	.23	

SDLMI Teacher's Guide

Self-Determined Career Development Model (SDCDM)

What is my goal?

What is my plan?

What have I learned?

Phase 1:
Set a Goal

Phase 2:
Take Action

Phase 3:
Adjust Goal or Plan

(Wehmeyer, Lattimore, Jorgensen., Palmer, Thompson, & Schumaker, 2003; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000)

Roles in SDCDM

Partner to identify and develop resources

Facilitator

Student/Person

Facilitator | Instructor | Advocate

Active Learner | Self-Directed Learner | Self-Advocate

Phases of the SDCDM

SDCDM
Self-Determination Career Design Model

SDCDM Phase 1: Set a Goal
Person Problem to Solve: What are my career and job goals?

Person Questions — **Facilitator Objectives & Primary Employment Supports**

1. What career and job do I want?

1a. Enable person to communicate career and job-related preferences, interests, beliefs, and values
- Person self-assessment of job and career preferences and abilities
- Job shadowing and Sampling
- Career and Job Exploration Activities

1b. Enable person to communicate strengths and needs as they relate to specific jobs and careers
- Communication skills training

1c. Enable person to prioritize career and job options and select preferred option(s)
- Decision-making, problem-solving instruction

2. What do I know about it now?

2a. Enable person to identify current status in relation to prioritized job and career option(s)
- Problem-solving, decision-making instruction

2b. Enable person to gather information about opportunities and barriers in their environments pertaining to prioritized job and career options
- Awareness training, self-advocacy instruction
- Job Shadowing and Sampling

3. What must change for me to get the job and career I want?

3a. Enable person to prioritize needs related to job and career preference(s)
- Decision-making, problem-solving instruction

3b. Enable person to choose a need to address from prioritized list
- Choice-making instruction

3c. Enable person to decide if actions will be focused toward capacity building, modifying the environment, or both
- Problem-solving, decision-making instruction

4. What can I do to make this happen?

4a. Enable person to state a long-term career goal, short-term employment goals, and objectives to reach short-term employment goals
- Goal-setting instruction

Go to Phase 2

SDCDM Phase 2: Take Action
Person Problem to Solve: What is my plan?

Person Questions — **Facilitator Objectives & Primary Employment Supports**

5. What actions can I take to meet my career or employment goal?

5a. Enable person to identify action alternatives to achieving career or employment goal
- Decision-Making Instruction

5b. Assist person in gathering information related to consequences of action alternatives
- Decision-Making Instruction, Problem solving instruction

5c. Enable person to select best action alternatives
- Decision-Making Instruction

6. What could keep me from taking action?

6a. Enable person to identify barriers to implementing action alternatives
- Problem solving instruction

6b. Enable person to identify actions to remove barriers
- Problem solving instruction, Goal attainment strategies, Exploration of Community Resources and Supports

7. What can I do to remove these barriers?

7a. Collaborate with person to identify most appropriate employment supports to implement selected action
- Self-management, Communication skills training, Exploration of Community Resources and Supports

7b. Teach person knowledge and skills needed to implement selected supports
- Self-management, Organizational skills training

8. When will I take action?

8a. Enable person to determine schedule for action plan
- Self-scheduling

8b. Enable person to implement action plan
- Self-instruction

8c. Enable person to self-monitor progress
- Self-monitoring

Go to Phase 3

SDCDM Phase 3: Adjust Goal or Plan
Person Problem to Solve: What have I achieved?

Person Questions — **Facilitator Objectives & Primary Employment Supports**

9. What actions have I taken?

9a. Enable person to self-evaluate progress toward goal achievement
- Self-evaluation, self-recording

10. What barriers have been removed?

10a. Collaborate with person to compare progress with desired outcomes
- Self-monitoring, self-evaluation

11. What has changed to get me the job and career I want?

11a. Support person to re-evaluate goal if progress is insufficient
- Goal-attainment strategies

11b. Assist the person to decide if goal should remain the same or change
- Decision-making instruction

11c. Collaborate with person to identify if action plan is adequate or inadequate given revised or retained goal
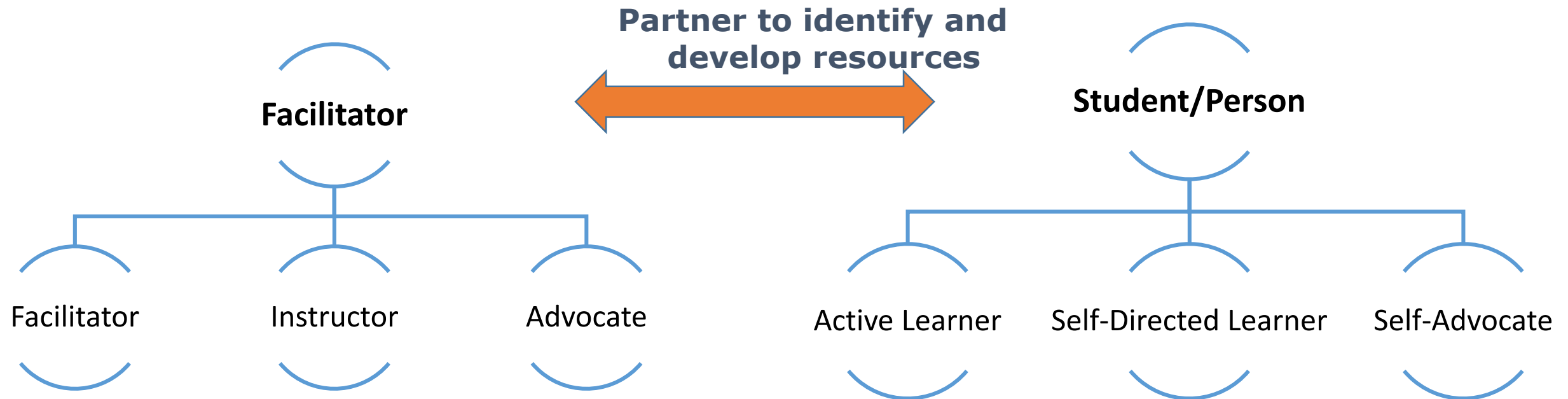- Self-evaluation, problem solving instruction

11d. Assist person to change action plan if necessary
- Decision-making instruction, self-management

12. Have I achieved what I want to achieve?

12a. Enable person to decide if progress is adequate, inadequate or if goal has been achieved
- Self-evaluation, self-reinforcement

12b. If goal has been achieved, support person to decide if a different goal is needed to achieve their employment or career goals
- Decision-making instruction, problem solving instruction, goal setting instruction

Set another goal or make a new action plan
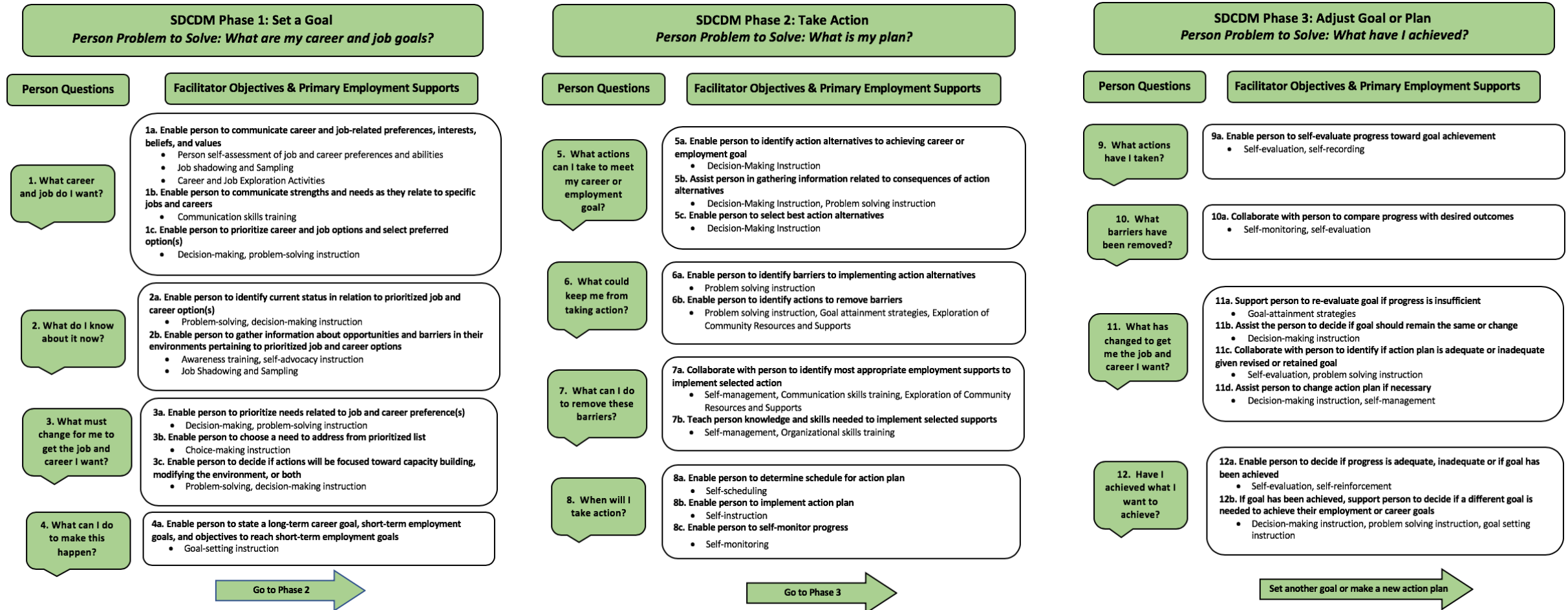
Phase 1: "What are my career and job goals?"

- Explicitly focused on a person's strengths, interests, and needs

- Follow a definite sequence so that the problem can be solved

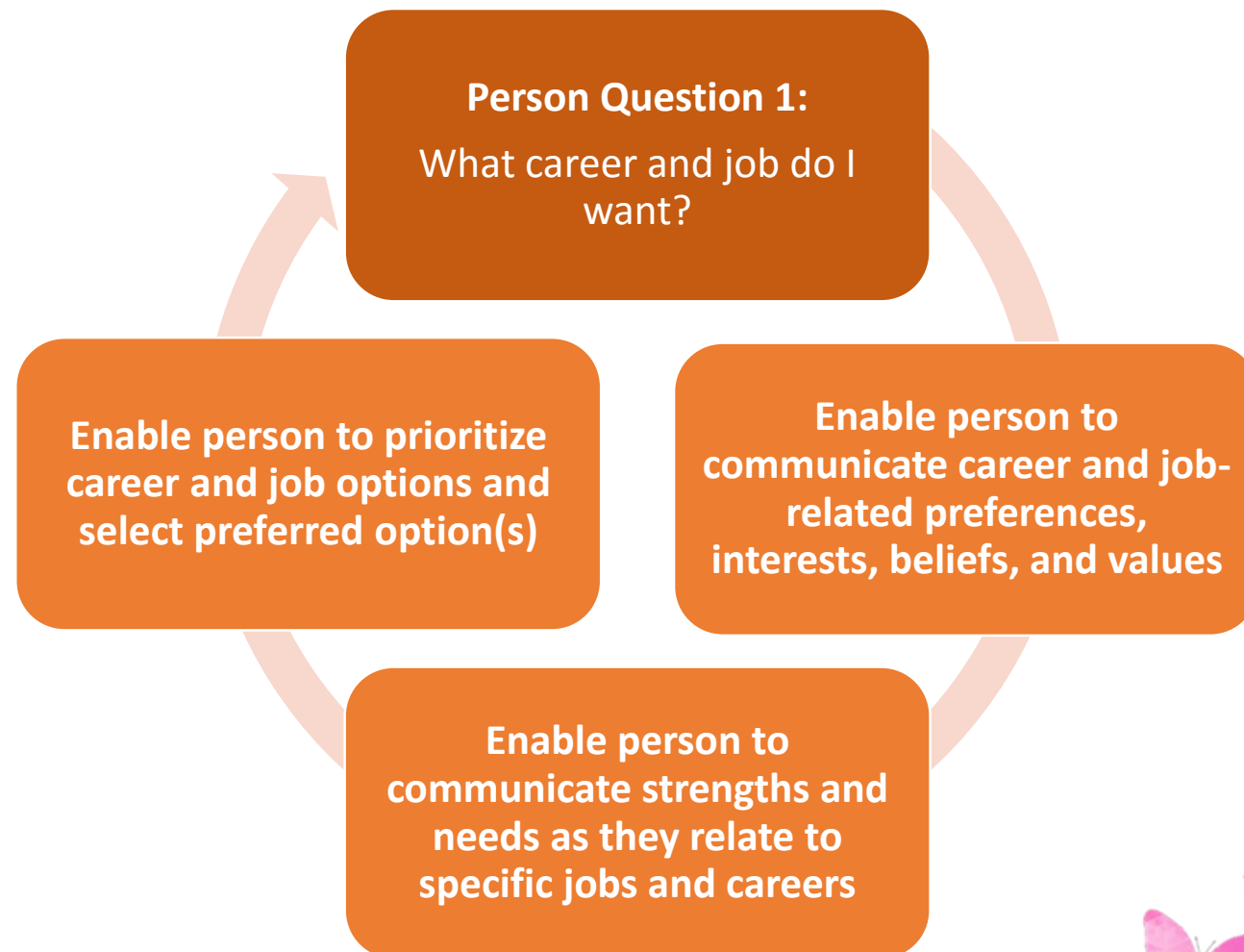- Enable a person to identify their career and job goals
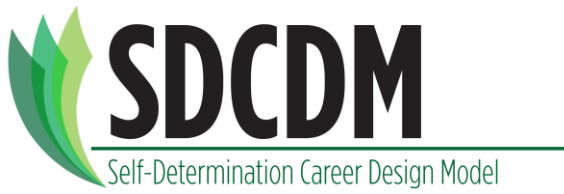
Phase 1 Person Questions

1. What career and job do I want?

2. What do I know about it now?

3. What must change for me to get the job and career I want?

4. What can I do to make this happen?

Phase 1: Facilitator Objectives

Facilitator Objectives: To support a person to answer the Person Questions using Employment Supports

- Example: When a person needs to decide what job or career they want, one of the facilitator's objectives is to enable the person to communicate career and job-related preferences.

Person Question 1:

What career and job do I want?

Enable person to communicate career and job-related preferences, interests, beliefs, and values

Enable person to communicate strengths and needs as they relate to specific jobs and careers

Enable person to prioritize career and job options and select preferred option(s)

Phase 1: Employment Supports

- Provide a means for facilitators to use individualized supports to enable persons to begin to teach themselves.

- Enable persons to:

  - Successfully self-direct their career design

  - Modify and regulate their own behavior

1. What career and job do I want?

1a. Enable person to communicate career and job-related preferences, interests, beliefs, and values
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THANK YOU!